**BABIES COUNT**
The National Registry for Young Children with Visual Impairments (aged birth to 36 months)

First Year Results: March 2016 to June 2017
Overall sample of 588 children

**Child Characteristics:**

**Gender**
- Male = 308
- Female = 280
- Total = 588

**Birth weight**
- Average weight = 5.98 lbs
- Smallest = 1.1lbs
- Largest = 15.2lbs
- Sample = 499
- Missing/unreported = 89

**Gestational age at birth**
- Full term = 332
- 37 to 33 weeks = 129
- 32 to 28 weeks = 44
- Less than 28 weeks = 53
- Total = 558
- Unreported = 30
Multiple births

- Single: 95%
- Twins: 5%
- Triplets: 0%

Primary Visual Condition: Both eyes

- CVI: 29%
- ONH: 11%
- ROP: 9%
- Structural: 6%
- Retinal: 4%
- Albinism: 3%
- Other: 22%
- Unknown: 16%

CVI = 171 Cortical Visual Impairment
ONH = 64 Optic Nerve Hypoplasia
ROP = 50 Retinopathy of Prematurity
Structural = 38 (aniridia, microphthalmia/anophthalmia, coloboma, corneal disorders, Goldenhar syndrome)
Retinal Disorders = 24 (Leber’s congenital amaurosis (LCA), retinoblastoma, familial exudative vitreoretinopathy (FEVR), other retinal conditions)
Albinism = 18
Other = 132 (nystagmus, strabismus, cataracts, glaucoma, ocular motor apraxia, optic atrophy, PHPV, hemianopia, nerve palsy/ptosis, choroidal hemangioma, aniscoria, and high refraction)
Unknown/undiagnosed = 91

Total = 588
### Additional Eye Conditions

<table>
<thead>
<tr>
<th>Secondary Visual Diagnosis</th>
<th>Right Eye</th>
<th></th>
<th>Left Eye</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>302</td>
<td>51.4%</td>
<td>321</td>
<td>54.6%</td>
</tr>
<tr>
<td>Refractive error</td>
<td>88</td>
<td>15%</td>
<td>80</td>
<td>13.6%</td>
</tr>
<tr>
<td>Nystagmus</td>
<td>87</td>
<td>14.8%</td>
<td>86</td>
<td>14.6%</td>
</tr>
<tr>
<td>Strabismus</td>
<td>78</td>
<td>13.3%</td>
<td>72</td>
<td>12.2%</td>
</tr>
<tr>
<td>Amblyopia</td>
<td>37</td>
<td>6.3%</td>
<td>20</td>
<td>3.4%</td>
</tr>
<tr>
<td>CVI</td>
<td>23</td>
<td>3.9%</td>
<td>23</td>
<td>3.9%</td>
</tr>
<tr>
<td>Optic Atrophy</td>
<td>22</td>
<td>3.7%</td>
<td>20</td>
<td>3.4%</td>
</tr>
<tr>
<td>Ptosis</td>
<td>14</td>
<td>2.4%</td>
<td>15</td>
<td>2.6%</td>
</tr>
<tr>
<td>Cataracts</td>
<td>8</td>
<td>1.4%</td>
<td>9</td>
<td>1.5%</td>
</tr>
<tr>
<td>Colobomas</td>
<td>7</td>
<td>1.2%</td>
<td>5</td>
<td>0.9%</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>6</td>
<td>1%</td>
<td>5</td>
<td>0.9%</td>
</tr>
<tr>
<td>OMA</td>
<td>4</td>
<td>0.7%</td>
<td>3</td>
<td>0.5%</td>
</tr>
<tr>
<td>Microphthalmia</td>
<td>3</td>
<td>0.5%</td>
<td>5</td>
<td>0.9%</td>
</tr>
<tr>
<td>PHPV</td>
<td>2</td>
<td>0.3%</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Hemianopia</td>
<td>2</td>
<td>0.3%</td>
<td>3</td>
<td>0.5%</td>
</tr>
<tr>
<td>ROP</td>
<td>2</td>
<td>0.3%</td>
<td>2</td>
<td>0.3%</td>
</tr>
<tr>
<td>Retinal disorder</td>
<td>1</td>
<td>0.2%</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Corneal disorder</td>
<td>1</td>
<td>0.2%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Vitreous hemorrhage</td>
<td>1</td>
<td>0.2%</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td><strong>total</strong></td>
<td><strong>688</strong></td>
<td>-</td>
<td><strong>672</strong></td>
<td>-</td>
</tr>
</tbody>
</table>

#### Number of Secondary Visual Diagnosis

<table>
<thead>
<tr>
<th>Number of Secondary Visual Diagnosis</th>
<th>Right Eye</th>
<th></th>
<th>Left Eye</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>302</td>
<td>51.4%</td>
<td>321</td>
<td>54.6%</td>
</tr>
<tr>
<td>One additional</td>
<td>218</td>
<td>37.1%</td>
<td>205</td>
<td>34.9%</td>
</tr>
<tr>
<td>Two additional</td>
<td>47</td>
<td>7.0%</td>
<td>45</td>
<td>7.6%</td>
</tr>
<tr>
<td>Three or more</td>
<td>21</td>
<td>3.5%</td>
<td>17</td>
<td>2.9%</td>
</tr>
</tbody>
</table>

#### Occurrence of etiology

- Prenatal = 232
- Perinatal = 87
- Postnatal = 113
- Total = 432
- Unreported/unknown = 156
Non-accidental trauma (NAT)

- Not an NAT = 555
- NAT = 26
- Total = 581
- Unreported/unknown = 7

Use of visual optics

- None = 408
- Glasses alone = 170
- Prosthesis = 4
- Both glasses and contacts = 3
- Contacts alone = 3
- Total = 588

Additional medical conditions

- Neurological = 58%
- Other = 40%
- Feeding issues = 33%
- None = 32%
- Global syndrome = 10%
- Deaf/hard of hearing = 7%
- Endocrine = 7%
Neurological = 338 (cerebral palsy/orthopedic impairment, seizures, congenital or acquired brain disorder, Autism Spectrum Disorder (ASD), spina bifida)
Other = 234 (cancer, technology dependent, heart condition, sleep issues, reflux/GERD, born with addiction, respiratory problems, allergies, viral sepsis infection)
Feeding Issues = 193
None = 185
Global syndromes = 57 (chromosomal, mitochondrial, hereditary, genetic, cranio-facial, metabolic disorders)
Deaf/hard of hearing = 43
Endocrine disorder = 38

Number of additional medical conditions

- None = 185
- One condition = 160
- Two conditions = 101
- Three conditions = 69
- Four conditions = 47
- Five or more conditions = 26
- Total = 588

Presence of developmental delays

- None = 14%
- Cognitive = 63%
- Language = 68%
- Social = 51%
- Fine Motor = 70%
- Gross Motor = 75%
- Adaptive = 52%
Developmental delays were reported individually or non-concurrently. None = 82 total sample had no additional developmental delays concurrent with visual impairment.
Cognition = 368
Language = 399
Social = 302
Fine Motor = 414
Gross Motor = 438
Adaptive = 306

**Number of developmental delays**

None = 82
One domain = 52
Two domains = 62
Three domains = 51
Four domains = 45
Five domains = 64
All six domains = 232
Total = 588

**Level of functional vision**

Low vision = 241
Typical or near typical vision = 142
Functions at the definition of blindness (FDB) = 127
Meets the definition of blindness (MDB) = 78
Total = 588
Level of support needs

- Typical: 14%
- Mild/Moderate: 50%
- Intensive: 36%

Mild/moderate support needs = 294
Intensive support needs = 213
Typical support needs = 81
Total = 588

Primary learning channel

- Visual: 58%
- Auditory: 12%
- Tactual: 30%
- Unknown/unreported: 12%

Visual = 274
Auditory = 144
Unknown/unreported = 113
Tactual = 57
Total = 588
Family Characteristics:

Ethnicity

- White: 49%
- Hispanic: 27%
- Black: 7%
- Native American: 7%
- Asian: 5%
- Pacific Islander: 3%
- Missing/unreported: 2%
- Middle Eastern: 1%

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>325</td>
</tr>
<tr>
<td>Hispanic</td>
<td>181</td>
</tr>
<tr>
<td>Black</td>
<td>49</td>
</tr>
<tr>
<td>Native American</td>
<td>45</td>
</tr>
<tr>
<td>Asian</td>
<td>32</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>19</td>
</tr>
<tr>
<td>Missing/unreported</td>
<td>11</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>667</td>
</tr>
</tbody>
</table>

Multiple Ethnic Makeup of Child

- One group: 89%
- Two groups: 9%
- Three or more groups: 2%

<table>
<thead>
<tr>
<th>Multiple Ethnic Makeup of Child</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>One group</td>
<td>512</td>
</tr>
<tr>
<td>Two groups</td>
<td>54</td>
</tr>
<tr>
<td>Three or more groups</td>
<td>11</td>
</tr>
<tr>
<td>Missing/unreported</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>588</td>
</tr>
</tbody>
</table>

Primary language

- English: 82%
- Not English: 18%

<table>
<thead>
<tr>
<th>Primary language</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>478</td>
</tr>
<tr>
<td>Not English</td>
<td>108</td>
</tr>
<tr>
<td>Missing/unreported</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>588</td>
</tr>
</tbody>
</table>
Two biological parents = 435
Single biological parent = 105
Foster/adoptive parent = 35
Other adult = 12
Missing/unreported = 1
Total = 588

No siblings = 316
One sibling = 137
Two siblings = 78
Three or more siblings = 57
Total = 588

Age of Biological mother and father at the birth of child

Teens: 9% Mom, 3% Dad
Twenties: 49% Mom, 40% Dad
Thirties: 36% Mom, 45% Dad
Forties: 6% Mom, 11% Dad
Fifties: 0% Mom, 1% Dad
Age of Mother

15-19 years = 38
20-29 years = 198
30-39 years = 144
40-46 years = 23
Missing/unreported = 185
Total = 588

Average age = 28.3 years
Youngest = 15
Oldest = 46

Age of Father

16-19 years = 12
20-29 years = 140
30-39 years = 157
40-49 years = 38
50-56 = 2
Missing/unreported = 239
Total = 588

Average age = 31.2 years
Youngest = 16
Oldest = 56

Level of education for mother and father

Mother's level of education

Did not graduate HS = 32
High school graduate = 122
Associate’s degree or some college = 151
Undergraduate degree = 89
Graduate degree = 49
Missing/unreported = 145
Total = 588

Father's level of education

Did not graduate HS = 37
High school graduate = 114
Associate’s degree or some college = 116
Undergraduate degree = 80
Graduate degree = 42
Missing/unreported = 199
Total = 588
Service Characteristics:

State

<table>
<thead>
<tr>
<th>State</th>
<th>18%</th>
<th>12%</th>
<th>29%</th>
<th>23%</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>104</td>
<td>70</td>
<td>173</td>
<td>136</td>
</tr>
<tr>
<td>Maryland</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Mexico</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utah</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>58%</td>
<td>8%</td>
<td>29%</td>
<td>23%</td>
</tr>
</tbody>
</table>

Age of medical diagnosis of visual impairment
- Average age of diagnosis = 7.2 months
- Variance = 42.7 months
- Standard deviation = 6.5 months
- Youngest age = 0 months
- Oldest age = 36 months
- Sample size = 502
- No diagnosis = 85 (not included in the analysis)
- Missing/unreported = 1

Months between diagnosis of visual impairment and referral to specialized visual impairment services
- Average months between = 5.2 months
- Variance = 33.6 months
- Standard deviation = 5.8 months
- Lowest = 0
- Highest = 26.1
- Sample size = 348
- No diagnosis = 85
- Diagnosis AFTER referral = 152
- Missing/unreported = 3

Age of referral to specialized visual impairment services
- Average age of diagnosis = 9.5 months
- Variance = 50.3 months
- Standard deviation = 7.1 months
- Youngest age = 0.2 months
- Oldest age = 33.2 months
- Sample size = 586
- Missing/unreported = 2
Referral source to specialized visual impairment services

- EI Program: 5%
- Medical Provider: 17%
- Family: 78%

EI Program = 457
Medical = 98
Family = 30

Specialized Visual impairment service provider

- Certified Visual Impairment Professional: 36%
- Other professional trained by VI program: 64%

Certified teacher of VI = 332
Other professional trained by VI program = 209
Certified O&M specialist = 11
Deaf blind specialist = 3
CTVI/O&M = 22
CTVI/DB specialist = 6
CTVI/DB/O&M = 1
Certified vision rehabilitation therapist = 4
Total = 588

Frequency of specialized visual impairment service

- Weekly: 43%
- Bi-weekly: 17%
- Monthly: 3%
- Other: 3%
- Quarterly or less: 17%

Weekly = 91
Bi-weekly = 209
Monthly = 243
Quarterly = 29
Other = 3
Bi-monthly = 9
Annual = 1
Consultation as needed = 3
Total = 588
Location of specialized visual impairment service

- Home: 97%
- Other: 3%

Number of other early intervention services (concurrent with VI Service)

- None: 21%
- 1 Service: 21%
- 2 Services: 23%
- 3 services: 7%
- 4 or more services: 28%

Early intervention services

- Physical therapy: 61%
- Occupational therapy: 60%
- Special instruction: 59%
- Speech/language services: 33%
- Other*: 17%
- None: 7%
- Deaf/Hard of hearing services: 4%

Physical Therapy = 361
Occupational Therapy = 354
Special instruction = 344
Speech/Language services = 194
None = 42
Deaf/Hard of hearing services = 23
Other = 97; includes social work, nursing, other non-idea service like music therapy or hippo-therapy, feeding/nutrition, psychological, assistive technology, applied behavior analysis
Total = 1415